

Endometriosis CARE Act of 2022

BACKGROUND

More than 1 in 10 reproductive-age women in the United States are living with endometriosis, which occurs when tissue similar to the lining of the uterus grows outside the uterus.¹ According to the Eunice Kennedy Shriver National Institute of Child Health and Human Development, the most common symptoms of endometriosis are pain and infertility.² Other common symptoms include:

- Painful or even debilitating menstrual cramps, which may get worse over time;
- Pain during or after sex;
- Pain in the intestine or lower abdomen;
- Painful bowel movements or painful urination during menstrual periods;
- Heavy menstrual periods;
- Premenstrual spotting or bleeding between periods; and
- Problems getting pregnant.

Despite the significant impact of endometriosis on the lives of women who are affected by it, the normalization of women's pain and the stigmatization of menstrual issues have resulted in a lack of scientific innovation and public awareness for the condition.³

The bipartisan **Endometriosis CARE Act**, led by Representative Lauren Underwood (IL-14), will finally fund the investments that are needed to advance endometriosis research, develop and expand access to treatments, and promote public awareness.

SUMMARY

The **Endometriosis CARE Act** would:

- Invest \$30 million per year in **endometriosis research** through the National Institutes of Health;
- Identify **barriers to accessing treatments for endometriosis symptoms**, such health care coverage, transportation, and health care professional shortages.
- Establish a national campaign to promote **public awareness** about endometriosis;
- Facilitate the dissemination of information about **evidence-based endometriosis care** to health care professionals and health systems; and
- Commission a **national study on disparities in endometriosis prevalence, detection, treatments, and outcomes** by key demographic characteristics.

ORIGINAL COSPONSORS

The **Endometriosis CARE Act** is cosponsored by Representatives Nikema Williams (GA-05); Alma S. Adams, Ph.D. (NC-12); Jenniffer González-Colón (PR-At Large); Al Lawson (FL-05); Jahana Hayes (CT-05); Adriano Espaillat (NY-13); and Mark Pocan (WI-02).

CONTACT

For more information, contact Jack DiMatteo in Rep. Underwood's office at Jack.DiMatteo@mail.house.gov.

¹ U.S. Department of Health and Human Services Office on Women's Health: Endometriosis. <https://www.womenshealth.gov/a-z-topics/endometriosis>. Accessed April 18, 2022.

² Eunice Kennedy Shriver National Institute of Child Health and Human Development: What are the symptoms of endometriosis? <https://www.nichd.nih.gov/health/topics/endometri/conditioninfo/symptoms>. Accessed April 18, 2022.

³ Society for Women's Health Research: Endometriosis and Fibroids Network. <https://swhr.org/science/networks/endometriosis-and-fibroids/>. Accessed April 18, 2022.

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Endorsements

A Better Balance	Melinated Moms
Alliance for Black NICU Families	Momma's Village-Fayetteville, Inc
American Association for	Mothering Justice
Psychoanalysis in Clinical Social Work	National Association of Nurse
American College of Nurse-Midwives	Practitioners in Women's Health
American College of Obstetricians and	National Birth Equity Collaborative
Gynecologists	National Health Law Program
Ancient Song Doula Services	National Medical Fellowships
Arika Trim Foundation	National Partnership for Women &
Association of Maternal & Child Health	Families
Programs	National WIC Association
Atlanta Doula Collective, Inc.	National Women's Health Network
Babyscripts	NETWORK Lobby for Catholic Social
Black Mamas Matter Alliance	Justice
Ceeing You Through	Physician Assistant Education
Childbirth Survival International	Association
Center for Law and Social Policy	Postpartum Support International
(CLASP)	PreemieWorld, LLC
Cookie La Doula, LLC	Rural Nurse Organization
Council of Public Health Nursing	Santa Barbara Women's Political
Organizations	Committee
Endo What?	Shades of Blue Project
Endometriosis Association	Society for Public Health Education
Endometriosis Foundation of America	Society for Women's Health Research
Every Mother Counts	The Endometriosis Summit
GLO Preemies	Urban Baby Beginnings
Jacobs Institute of Women's Health	Wayne State University
Japanese American Citizens League	What to Expect Project
JMM Health Solutions	Wisconsin Alliance for Women's Health
KoKo Kares Doula Services, LLC.	Women First Research Coalition
March of Dimes	Yeye's Gift Doula Services, LLC
Maternal Mental Health Leadership	
Alliance	

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Quotes in Support

“Thank you to Representatives Lauren Underwood and Nikema Williams and the House Endometriosis Caucus for creating the Endometriosis Care Act and carrying forward this long-overdue correction to how we regard women's reproductive health issues. I started EndoFound thirteen years ago with my surgeon, Dr. Tamer Seckin, so we could create awareness and support the millions of individuals in the U.S. who have endometriosis. We need to make sure that ALL individuals with endometriosis have access to the information and care they need and I believe that the Endometriosis Care Act will do just that.” - **Padma Lakshmi, Co-Founder, EndoFound**

“As one of the at least 1 in 10 women who have endometriosis, I know personally how overlooked and underfunded it has been and how we are decades behind where we should be in research. While in Congress, I went to work to establishing the first ever bipartisan Endometriosis Caucus and helped pass long overdue and necessary additional funding for the disease. Rep. Lauren Underwood was not only a supportive friend during that process, she too was an advocate. I'm so happy to see these champions step up and thank Rep. Underwood and Rep. Williams for their efforts in introducing the Endometriosis CARE Act. With new resources dedicated to endometriosis research and bringing more attention to this debilitating illness through this legislation along with re-establishment of the bipartisan Endometriosis Caucus, we can help fewer women feel alone and get the diagnosis and treatment they need to help manage this disease and have a better quality of life.” - **Abby Finkenauer, Ambassaor, EndoFound**

“Those who live with endometriosis all too often also live with pain and with unanswered questions. In order for obstetrician-gynecologists to care for our patients with endometriosis, we need information on prevention and early diagnosis, and on much needed innovative treatment options. We also need to better understand how to reach our patients and connect them to the care that may help improve their lives. We are grateful to Representatives Lauren Underwood, Nikema Williams, Jenniffer González Colón, and Alma Adams for their leadership in ensuring that people who live with endometriosis are not overlooked, and that endometriosis research has the federal support it deserves.” - **Iffath Abbasi Hoskins, MD, FACOG, President, American College of Obstetricians and Gynecologists (ACOG)**

“SWHR thanks Representative Underwood for her leadership on the Endometriosis CARE Act of 2022. Endometriosis is prevalent (affecting more than 1 in 10 reproductive-age women in the United States) and costly—and still, it is under-researched and

underfunded. This legislation will not only provide critically needed funding to advance our understanding of endometriosis and develop diagnostic and treatment options, but it will also help bring awareness to this disease and reduce its stigma. SWHR applauds this legislation, which will make tremendous strides in improving women's health, and encourages members of Congress to pass this bill without delay." - **Society for Women's Health Research**

"The Endometriosis CARE Act is truly a breakthrough in recognizing that health disparities play a major role in the lack of attention endometriosis has received. Besides overall gender disparities, disparities based on race and ethnic minority status, socioeconomic background, disability status, insurance status, health care provider access (woefully inadequate in endometriosis!), lack of respectful and substantial medical education on the disease and its related health problems, and more, play critical roles in the ability of women and girls with endometriosis to attain well-being and lead the life they had planned. Currently, too many are doomed to years of pain, disability, inability to pursue their full education or career/work of their choice. And infertility may top the suffering for roughly 40%. We are deeply grateful to Representatives Nikema Williams and Lauren Underwood and the Congressional Endometriosis Caucus for their leadership." - **Mary Lou Ballweg, President/Executive Director, Endometriosis Association**

"We as a nation can do more to address the significant impact of endometriosis on the lives of women who are affected by it, and the Endometriosis CARE Act, led by Rep. Lauren Underwood, will finally provide the investments we need to advance endometriosis research, develop and expand access to treatments, and promote public awareness. Postpartum Support International and its hundreds of chapters, applaud the leadership of Rep. Underwood and stand in support of this needed legislation." - **Wendy N. Davis, PhD, PMH-C, Executive Director, Postpartum Support International**

"Inequitable access to health care presents critical barriers for women of color to be properly diagnosed and treated for endometriosis. The Endometriosis CARE Act of 2022 is an essential investment to lower these barriers and ensure all women receive the care needed to treat this painful disease that is often associated with infertility. National Medical Fellowships strongly supports passage of this bill, which will help reduce health disparities." – **National Medical Fellowships**

"The Endometriosis CARE Act takes a comprehensive approach to help women who live with endometriosis, through expanding research, reducing barriers to treatment, launching educational efforts for both patients and health care providers, and addressing health disparities. Rep Underwood's leadership and understanding of how to truly improve the lives and health of those with endometriosis is to be applauded." - **Jacobs Institute of Women's Health**

“Women's health issues often go overlooked and undiagnosed due to systemic failures, old data, and the normalization of women's pain. Babyscripts is excited to endorse the Endometriosis CARE Act to begin to resolve some of these issues, and put important resources toward better women's health.” - **Babyscripts**

“The addition to support the effects of endometriosis through research and care is vital to the health of potential new birthing people across this country. As we continue to support families affected by endometriosis, we are thrilled to support the Endometriosis CARE Act.” - **Momma's Village-Fayetteville, Inc**

“The normalization of extreme pain and discomfort surrounding women's reproductive health have been perpetuated for far too long. Therefore, the enactment of the Endometriosis CARE Act is long overdue and much deserved by women across the nation.” - **Cookie La Doula, LLC**